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# Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning

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## ABSTRACT

**Background:** Advance care planning (ACP) is increasingly prominent in many countries; however, the evidence base for its acceptability and effectiveness is limited especially in conditions where cognition is impaired, as in dementia.

**Method:** This qualitative study used semi-structured interviews with people with mild to moderate dementia ( $n = 17$ ) and family carers ( $n = 29$ ) to investigate their views about planning for their future generally and ACP specifically.

**Results:** People with dementia and their families make a number of plans for the future. Most people undertook practical, personal, financial, and legal planning. However participants did not make formal advance care plans with the exception of appointing someone to manage their financial affairs. Five barriers to undertaking ACP were identified: lack of knowledge and awareness, difficulty in finding the right time, a preference for informal plans over written documentation, constraints on choice around future care, and lack of support to make choices about future healthcare.

**Conclusions:** Health and social care professionals can build on people's preferences for informal planning by exploring the assumptions underlying them, providing information about the possible illness trajectory and discussing the options of care available. Health and social care professionals also have a role to play in highlighting the aspects of ACP which seem to be most relevant to the wishes and aspirations of people with dementia.

**Key words:** advance care planning, dementia, qualitative research, ageing, carers

## Introduction

Over the last two decades initiatives and policies to help people have more control over decisions about their healthcare have increased in many countries. Advance care planning (ACP) is an example of one such policy. The origins of ACP can be traced back to the development of advance directives in the United States: these were initially termed “living wills” and allowed people to refuse in advance invasive life-prolonging treatments (Patient Self Determination Act: 1990; Boyd *et al.*, 2010).

Limitations of former advance directives have resulted in efforts to broaden the decision-making process for people in regard to their future care and pay attention to the process of decision making as well as content (Teno, 2004; Berger, 2010). ACP has been relatively infrequent in the UK until the last decade; a summary of the formal outcomes of ACP discussions, are presented in Box 1.

In order to undertake ACP, a person must have mental capacity. In the UK, the issue of mental capacity as integral to ACP has been emphasized in recent professional guidance (National Institute for Clinical Excellence, 2010; NHS National End of Life Care Programme, 2011): in England and Wales the Mental Capacity Act 2005 (MCA) provides the statutory framework for decision making in an individual's best interests when they lose capacity to make their own decisions.

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## Box 1. Definition and formalized outcomes of ACP

### Definition of ACP

... a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses'. (NHS End of Life Care Programme, 2011)

### Outcomes of ACP

- Statement of wishes and preferences: Documents an individual's wishes and preferences for future care but is not legally binding. In England and Wales, this is known as an advance statement.
- An advance directive for refusal of treatment (originally known as a "living will"): This comprises a statement of an individual's refusal to receive specific medical treatment in a predefined potential future situation. It comes into effect when a person loses mental capacity. In England and Wales, this can be legally binding and is known as an ADRT.
- Power of attorney (POA): This is a formal arrangement, undertaken by deed, whereby the person ("the donor") nominates another (the "donee" or "attorney") to act in his or her name or on his or her behalf. In England and Wales, a new type of power of attorney, a Lasting Power of Attorney (LPA), allows the donor to confer authority on the attorney to make decisions, including decisions in circumstances where the donor no longer has capacity. LPAs can be made in relation to two separate aspects: (1) the donor's health and personal welfare and (2) the donor's property and affairs.

Recent UK research has revealed older people in general have limited interest in ACP, tending to have a "live for today" attitude (Samsi and Manthorpe, 2011). In illnesses such as dementia, ACP guidance recommends that ACP is carried out early in the illness while the patient still has capacity to make these decisions (National Institute for Clinical Excellence/Social Care Institute of Excellence, 2006). Research suggests that ACP discussions may be being carried out too late in the illness when patients do not have capacity (Denning *et al.*, 2011; Robinson *et al.*, 2012). A recent review (Denning *et al.*, 2011) also found that family carers of

people with dementia have unmet needs in terms of support, information, and education, in relation to undertaking ACP. However, there has been limited research to date (Denning *et al.*, 2011) exploring the views of people with dementia about ACP and how, when and where, such discussions should occur. The aim of this qualitative study was to explore, through interviews, the views, and experiences of people with dementia and family carers on the content, process, and timing of ACP.

## Methods

The study was conducted in the North East of England and was approved by the Newcastle and North Tyneside 1 Research Ethics Committee (REF 09/H0906/5).

### Recruitment and data collection

Potential participants with dementia were identified by healthcare professionals from local older people's services. Our inclusion criterion was people with mild/moderate dementia, as indicated by a Mini Mental State Examination (MMSE); (Folstein *et al.*, 1975) score of 21 or greater; however, professionals could identify people with a lower score if they felt individuals had the capacity to participate. As so little is known about what people with dementia and carers think about ACP the inclusion criteria was kept open and the focus of the study was not narrowed beyond that of a carer or person with mild-moderate dementia. This is appropriate when there is uncertainty about an issue (Daly *et al.*, 2007). Interviews continued until analysis suggested data saturation had been reached. Potential participants were sent an invitation letter and study information sheet. This was followed up with a telephone call by a known healthcare professional to evaluate level of interest. The details of interested participants were passed on to the research team who then contacted potential participants and arranged the interviews at a convenient time and location.

Participants were given the option of being interviewed alone or together. In addition to the above sampling procedure, some informal carers volunteered to take part in the study after hearing presentations on the study by the research team at peer support groups run by voluntary agencies. Before data collection commenced, researchers ensured participants had capacity to take part by explaining the study and assessing whether the potential participants could understand, retain, and weigh up the information as well as communicate their decision. Written informed consent was gained from participants.

## Box 2. Areas covered by the interview topic guide

For all participants:

- Attitudes and feeling about planning for the future
- Exploration of potential good and bad points of ACP
- Exploration of circumstances in which ACP may be useful
- Exploration of views about ACP for self or person they care for

For those interested in ACP explore:

- How would they like to do ACP? With whom? When?
- Reactions to ACP documentation
- Most and least important aspects for ACP
- Plans already put in place
- If they have not made any plans explore the reasons why

Semi-structured interviews were used to explore the views and experiences of participants (see Box 2). The interviews were conducted by experienced researchers (CB and CD); in addition to the topic guide, the researchers used a prompt sheet (which outlined definitions of the three types of ACP documents as seen in Box 1) and examples of ACP documentation (an advance statement developed and used by a local NHS Trust, an Advance Decision to Refuse Treatment (ADRT) from Dignity in Dying, an ADRT from the NHS End of Life Care programme, and the Physician Orders for Life-Sustaining Treatment – POLST) to help participants understand the core components of ACP and to help them envisage the process and potential outcomes of any ACP discussion. Interviews lasted up to 60 minutes and were digitally recorded and transcribed verbatim.

## Data analysis

Members of the research team (CB, CD, CEx, and LR) familiarized themselves with the data by repeated reading of transcripts. A coding framework was developed through the application of thematic analysis (Braun and Clarke, 2006) and codes were added to and changed iteratively as the team worked through the entire dataset. Ongoing analysis by the team led to the generation, reviewing, and refining of themes and sub themes. Thematic analysis was chosen because it offers flexibility as an analytic method, can summarize key features of a large dataset whilst also offering “thick description” and allow for social as well as psychological interpretation of the data (Braun and Clarke, 2006).

NVivo (Version 9) facilitated data management. Extracts from interviews are identified with the following codes: *R* refers to the unique identifying number given to each research participant, *PWD* identifies that the quotation is from a person with dementia and *carer* is used to identify family carers. In addition, age and gender is provided for people with dementia and the relationship to the person with dementia is provided for carers.

## Results

Thirty four interviews were conducted involving 17 people with dementia and 29 carers. Twelve interviews were conducted jointly, 5 were conducted with a person with dementia only and 17 were conducted with a family carer only. Participants represented a range of diagnoses of dementia including Alzheimer’s disease, Huntington’s disease, dementia with Lewy bodies, Vascular, and mixed (Alzheimer’s disease and Vascular dementia). More men with dementia were interviewed ( $n = 12$ ) than women ( $n = 5$ ) but carers were more likely to be women ( $n = 19$ ) than men ( $n = 10$ ). People with dementia ranged in age from 46 to 93 years and carers ranged in age from 44 to 89 years. The sample included one participant with early onset dementia and his spouse. Carers were typically spouses of the person with dementia but on four occasions were adult children of the person with dementia. The views of family carers have not been used as proxies for people with dementia but to explore the experience and views of people who care for people with dementia. Family carers and people with dementia may both have different, but equally valid, experiences, and needs.

The main theme to emerge from the data was that people living with dementia did undertake practical, personal, and financial future planning; however, they had difficulty making formal plans for their future healthcare. The barriers to making formal plans for their health and welfare were identified as a lack of awareness and knowledge of ACP, difficulty in finding the right time, a preference for informal discussions and plans, constraints on choice around future care options and a lack of support to undertake ACP.

## The plans people did make: “Getting my house in order”

When discussing planning for the future, people with dementia and carers reported putting a number of plans in place. Most commonly participants discussed aspects of financial planning such as making wills, appointing someone to act as power of attorney for financial matters and putting their

assets into trust. People also discussed making very personal plans such as writing letters to loved ones to be opened after their death and organizing all their important documents into one place so they would be easily retrievable during ill health or after their death.

Planning for ill health was a consideration for some participants in that they discussed making adaptations to their homes to enable them to remain independent for as long as possible, e.g. installing a level access shower. Participants also reported making plans for their own funeral, such as choosing and paying for a funeral plan, and choosing songs or readings they would like at their funeral service. The main motivations for making these plans were often concerns over the costs of funeral services and a desire to make things as easy as possible for their family members during periods of ill health or after their death.

... the will is made and it's just the funeral, pay for that. I'm doing it next week because I've just read that at the end of November all the fees are going up again. (R173, Carer, Wife)

I didn't really want to think about popping my clogs but no but it was something that had to be done [had completed a will and enduring power of attorney] . . . And that was it . . . It saves the family a lot of trouble (R174, PWD, Female, 87 years)

### **Aspects of ACP undertaken: Lasting power of attorney for property and affairs**

Although participants were comfortable making practical, personal, and financial plans, their knowledge about ACP was largely limited to LPAs for property and affairs or, since many participants had undertaken the process prior to the introduction of LPA in 2007, the older form known as an Enduring Power of Attorney (EPA). The decision to complete the financial aspect of LPA (or EPA) was often made at the same time as completing a will. Solicitors played an important role in highlighting the possible benefits of appointing a power of attorney, often attending peer support groups to discuss the importance of power of attorney and the possible negative consequences if it were not undertaken. It came as a surprise to many participants to be told that their assets could be frozen if they held a joint bank account with their spouse or partner and one of them lost capacity for example.

We went to see the solicitor and one of the things he pointed out was that if the banks or anybody find out they can actually freeze your assets and that was the bit

that came at me a hundred mile an hour. (R56, Carer, Wife)

Participants reported that undertaking the process of completing a power of attorney, be it LPA for property and affairs or EPA, was relatively straightforward if they went through a solicitor.

My mam died and we decided to look into it through [voluntary agency]; [voluntary agency] got us a solicitor, he came out sorted everything out that we needed and for the future made sure we had the enduring power of attorney in case anything was to happen down the line and it was too late to retrospectively sort it out; it's all in place. (R141, Carer, Son)

Only one couple had attempted to complete the application for a LPA without legal support but they found the form complicated and sought advice from a voluntary agency. The need to appoint an attorney for financial matters was something that was often linked to the uncertainty of getting older, and sometimes simply the uncertainty of life. Dementia was seen to make power of attorney for financial matters even more important, but it was perceived as important even when dementia was not a factor.

I've done power of attorney yeah . . . Just in preparation of getting older, because nobody lives forever and I was prepared, so it's all done. (R129, PWD, Male, 77 years)

Whilst participants generally had a higher awareness of LPAs for property and affairs, the same was not true of other ACP components. A number of barriers to undertaking ACP in general were identified.

### **Barriers to undertaking ACP whilst living with dementia**

Five barriers to undertaking ACP were identified: lack of knowledge and awareness, finding the right time, a preference for informal discussions, and plans rather than formal written documentation, constraints on choice around future care options, and lack of support to make choices about future healthcare.

#### **Lack of knowledge and awareness**

Despite being knowledgeable and aware of where to find help about LPAs for property and affairs, very few participants were aware of the LPA for health and personal welfare, perhaps due to its relatively recent introduction in England and Wales; they were also typically unaware of advance statements



or ADRTs. Where participants did have some knowledge of ADRTs they often referred to them as “living wills” highlighting the difficulty of changes in terminology. The participants who had some knowledge of ADRTs were usually those few who had direct experience of documenting their decision to refuse treatment in advance.

It was just . . . I suppose it was just the financial side that that they talked about. I didn't realize there was two different ones. (R56, Carer, Wife)

I went within months [of father dying] to make a living will because I just didn't want to be a cabbage. I didn't want my son and daughter to experience what I'd experienced with dad and I didn't want them to have to make any decisions. (R125, Carer, Wife)

Not only did participants report a lack of awareness about most components of ACP, they also felt that they lacked specific knowledge both about the range of services available and/or about the likely progression of dementia to be able to participate meaningfully in such a process. For example, identifying a preferred place of care is often included in advance statements. However, participants felt that the current social care system in England was very complicated, with multiple providers of care including local authorities, NHS, and private companies. Coverage in the media also played a role in highlighting to participants that costs of care could be problematic and were not easily understood. Participants stated they could not begin to identify a preferred place of care until they were clear of the financial and social implications of their decisions. The costs of care and the differences between care providers were factors identified which might influence choice of place of care.

Well the only thing I want now at the moment is to know what private care costs, I mean obviously if I wasn't going into private care or whatever care [until] two years' time, what they say it costs now would be less than what it's going to cost then but I want to know the cost of private care now and the cost of . . . is it public, council care? (R140, PWD, Male, 84 years)

Some participants also reported they did not receive a satisfactory level of information about the implications of a diagnosis of dementia. Some carers felt that they had never been prepared for what to expect in the future and this prevented them from making appropriate plans. These participants were often looking back to a diagnosis that had occurred many years ago and recognized that the situation may be different now.

I think it's a bit more open now, but at the time I had actually no idea what this illness involved. I thought it was you lose your memory about things – the past and sort of family and stuff like this. But we didn't realize that other things like speech, the physical side, went down the pan. (R177, Carer, Son)

### Finding the right time

A second barrier identified by participants was the issue of timing. Participants reported that they would be willing to engage in planning for their future healthcare; however, they felt the timing was not right for them just yet. The “right” time was hard for participants to define but often participants were confident that they would be able to judge when it was right for them.

. . . we're just sort of ignoring it for a while because it's not really affecting us in any great detail, so we're just plodding on . . . I mean they said you know two or three years maybe something like that, so there's no real urgency. (R183, PWD, Male, 72 years)

Whilst it was difficult to identify the right time to begin ACP discussions, participants were generally clear that the point around dementia diagnosis was not a good time. They articulated the difficulty they experienced coping with receiving a diagnosis of dementia for themselves or for a loved one. In many cases, it was reported that it took people years to accept a diagnosis and to begin to see beyond that, although this varied between participants.

I think if I go back to when [husband] was first diagnosed it took me three years to get my head around it, I really had a bad time with it at first, although I did think he had Alzheimer's. It was fine to think it but it was an absolute bombshell to have it actually told by a doctor . . . (R144, Carer, Wife)

Although the time of diagnosis was commonly seen as too early to begin the process of ACP, participants similarly felt that there was a clear period of time when it would be too late to discuss ACP. The difficulty for participants was predicting when someone would lose the capacity to make a specific decision. Dementia was seen to be unpredictable and participants believed that for some it may be years before they lost their capacity, for others it may be a much shorter time.

The trouble with dementia is it can take a long time, it can take a short time. So I don't know what's the best time to do it but personally I would rather do it when I still had my wits about me but of course [husband] doesn't have a clue what's going on now, so that's why it was done for him. (R171, Carer, Wife)

For some participants the idea of planning for future health was too difficult. Some people emphasized “living one day at a time” and did not want to make plans beyond this.

We tend not to think too far in advance. We’re tending to live each day as it comes. I don’t think we can do anything else can we? (R92, Carer, Husband)

I like making plans and not too far in advance though, you know, the likes of this week or possibly into next week . . . . (R140, PWD, Male, 84 years)

Other participants felt that decisions could only be made at the time when it was clear what they were facing. For others, the issue of time was linked with hope that the future would lead to an improvement in prospects. They hoped that a cure might be found in the future and as such they would not want to rule out any treatment options in advance.

I suppose like everything else you don’t know what, it depends what the problem is at the time doesn’t it. (R146, PWD, Male, 63 years)

I always say there’s so much research going on tomorrow you may find a cure. (R145, Carer, Wife)

However for a minority of participants who had felt that the timing was right and had undertaken some aspects of ACP, it was important to know that the ACP documentation would be regularly reviewed, ideally by a professional they already had a relationship with, as circumstances changed.

We only found out at the end that it’s going to be reviewed every six months . . . because things do change. They do. (R92, Carer, Husband)

### Preference for informal discussions

Participants had divergent views on the value of formal written ACP documentation as opposed to having discussions and making informal plans with family; the latter were considered more flexible and this was valued when there was so much uncertainty about the future. The most common informal plan discussed by participants was that of a family member making decisions on behalf of the person without capacity; many believed their families would make the right decision for them at the time. This view was voiced by both people with dementia and carers.

Yeah, I know she would do the right thing and she knows I would do the right thing you know so it’s not a problem. (R183, PWD, Male, 72 years)

For most participants, it was assumed that, if they or their loved one had lost capacity, family members would be consulted when medical decisions were needed. Participants did not talk of “best interest” decision making, which is how the MCA in England and Wales would frame such a process, but they based their beliefs on past experiences of family and friends. Family members were perceived as having a great understanding of someone’s wishes and desires, much greater than could be communicated on a form. A spouse or grown-up children were most often assumed to have the potential to act as a “surrogate” decision maker; this was often seen as being the same as next of kin.

We would talk amongst ourselves; we’d talk to our kids (right) because they’re obviously going to be involved at some stage or another. (R92, Carer, Husband)

Several carers assumed that they would be able to make decisions about treatment on behalf of the person with dementia should the need arise (even where they knew that their preferences conflicted with those of the person with dementia). Some carers who did not wish to prolong the life of the person with dementia were very reluctant to document these views since they felt guilty and disloyal. The written document could seem too harsh and inhumane.

I don’t think I could write it down [ . . . ] I would feel I was putting him to his death. (R145, Carer, Wife)

For others, written documents were seen to create more problems than they solved. They were seen to leave too many questions unanswered, were open to interpretation and could never cover all eventualities.

You see, if I don’t want any life extending treatment in the event that I am, that I will die quickly if I don’t have it. This is impossible to actually do because the medical people see me in whatever condition I’m in. Now, if I’m in a condition such as that I’m difficult to nurse, that I’m severely agitated say and difficult thereby to perform functions on, the medical profession must be allowed to administer drugs to make me manageable. (R170, Carer, Husband)

Whilst some people preferred the flexibility of informal plans, others were very keen to undertake ACP; the latter had often had a negative life experience, such as previous experiences of perceived poor care or lack of involvement in decision making and were seeking to avoid the same situation again.

So [if] it came to like the time that he was like that I could turn around and say “no that’s not what he wants and this is what he wants,” and I’d like to do that without someone saying “well you can’t do that” and just take it out of my hands because I know that’s not what he wants. (R201, Carer, Wife)

Although some participants had held informal ACP discussions with their families, they still would have liked help to develop more formal plans. For example, one carer discussed her concerns over what would happen to her husband if she could no longer manage or died. She had very informal discussions with her son who was clear that he did not want either of his parents to go into care and he would welcome them into his home. However, this participant discussed how uncomfortable she was with her son’s suggestion as it would mean living with her new daughter-in-law. She felt that this was too much of an imposition for someone she did not know well and would have liked to discuss other options with someone outside of the family.

Aha, that’s the only thing that worries me, if I was to go first because I know my son says he wouldn’t let us go in to a home but then on the other hand this might sound awful but she’s my third daughter in law. . . . and he is all we’ve got . . . (R180, Carer, Female)

The data suggest that formally recording wishes may be more important when people do not have close family or friends to provide an adequate informal back up or when they have had a negative experience and do not have faith in health and social care professionals.

### **Constraints on choice around future care options**

The fourth reason people reported that they did not make formal ACP documents, related to perceptions about choice, or the lack of choice, around future care options. Some participants felt their wishes were unlikely to be met even if they voiced them, due to limited care options in the current health and social care systems. For example, some participants would have liked to remain at home with 24 hour care if their health deteriorated; however, it was seen as futile to record this as it was perceived to be unlikely to be delivered unless they could finance 24 hour care themselves. Other participants felt that there was no immediate need to record their preferences as they were seen to be in line with current service provision. For example, most participants discussed their desire to remain in their own homes for as long as possible. It was believed that current statutory services would support people in this aim, to an extent.

I don’t think there’s any need to write it down because, I mean that first one about what would you and those close to you like to happen, that’s [Wife] and myself as I’ve said before, we’d like to be together and stay at home and have assistance if needed . . . (R195, Carer, Husband)

However, there was a perception that services would only be able to support people to remain at home to a certain point and if people needed a lot of personal care then it was likely they would have to enter residential or nursing care. Participants often reported that they did not want this option but many accepted that may be the only option available depending upon their needs.

Actually talking about going into care, I have no thoughts of going into care but . . . I know that there’s every possibility like other people I could have to go into care and I think about it. (R140, PWD, Male, 84 years)

Participants also discussed the limitations of care that supported people to stay in their own homes. Thus even when options were available to meet peoples’ wishes they were not always perceived to be of a high standard.

Eh, well what types of service are able to assist me with my care? Well I am not quite sure about that. I hear about people coming in to the house to help you, help you dress, and get etcetera but what I’ve heard is never very good. I’ve heard they come in and you can be put to bed at five o’clock at night and things like this. (R153, Carer, Wife)

### **Lack of support to make choices about future healthcare**

Participants reported a lack of help for people who wanted to make decisions about their future healthcare: many did not know who to turn to for advice about the three health-related components of ACP but had ideas about who they would prefer to help them. Financial planning, such as LPAs for property and affairs, was seen to be quite straightforward, involving a visit to a solicitor. In general, the voluntary sector, such as older peoples’ and dementia charities, the popular media, and family were all identified as important sources of information. Personal contacts were also important; some participants had family members with healthcare or legal expertise. They often encouraged and helped people to start making plans.

Now my son has given me other things to do hasn’t he. Well he says if I was ill how do I know where you keep your bills . . . It’s made us think about other



things that really I need to get my house in order. (R92, Carer, Husband)

Participants who had contact with dementia advisors often identified the role as one that they would like to help them through ACP.

The advisor at the Alzheimer's society, a matter of fact you've given me a train of thought, I will bring this subject up with them and, because he is that type of person, he's a very caring person. (R129, PWD, Male, 77 years)

For other participants, it was more variable who they would like to support them. In terms of ADRTs, it was seen that there was a need for someone with medical knowledge to be involved.

I think with something like that you've got to be led by somebody with medical knowledge haven't you. (R146, PWD, Male, 63 years)

Oh you've got to have the doctor there to explain it all. It's too complicated to . . . it's not a decision you can make yourself. (R171, Carer, Wife)

Accessing support could be difficult when people with dementia and family carers had different needs. One carer felt that she could not discuss dementia openly with her husband as she was concerned he would become upset. Therefore, she found herself asking for support and information in hurried conversations on the doorstep with the Carer Support Worker rather than more relaxed and detailed discussions.

If I've got something I really want to discuss with her [Carer Support Worker], I'll wait until I see her out [ . . . ] and then I get the information but I try not to talk about it in front of him because that's when he gets upset and I won't have him upset because he's dreadful when he gets upset. (R144, Carer, Wife)

Participants identified a need for more information about the breadth of decisions available under ACP; however, they also identified a need for this information to be paced so that they got the right level of information at the right time. Finding support was an area identified as difficult for some who wanted to get on and make plans. One participant discussed his frustration at not receiving sufficient support from health and social care professionals to facilitate his decision making in advance.

Yes, because some people will say, you know like a doctor or social worker or whoever it might be, one will say one thing and one will say something else. One

will treat it as what it is and one will just say well it's only memory problems and you know I feel like saying, give them a slap, and saying yes I know that's what it is now but who's to say what it's going to be in two years, five years, or ten years . . . (R194, PWD, Male, 46 years)

The data suggest that people with dementia and their families do not know who they should turn to for advice on ACP although they do have ideas about whom they would like to receive support from.

## Discussion

Previous research has shown that although older people can be resistant to planning in advance for serious illness they do plan for an area of the future that is certain, death (Carrese *et al.*, 2002). This study builds on the work of Carrese *et al.* by showing that the plans made by people with dementia and their family carers are often informal and flexible and most importantly concern areas which make sense to individuals and their family and over which they feel they have control. Our study sample preferred to focus on living for the present although if they do undertake ACP it is with the aim of reducing future burden/stress for their family. Not unreasonably participants felt it was impossible to know what the future would hold and how they, and their family, would cope as the illness progressed. Similar findings have been found in studies exploring the views of older people in general on ACP ((Hill *et al.*, 2007; Samsi and Manthorpe, 2011), including those living in care homes (Seymour *et al.*, 2010). In a survey across seven European countries (Daveson *et al.*, 2013) found that while involvement in decision-making was important to many there was a sizeable proportion of the public who expressed a preference not to make decisions about their care in advance of incapacity, highlighting the role of surrogate decision-making. In other studies, older people have expressed a reliance on family members, or a trusted health professional, to assume responsibility for future "best interests" decisions about their health (Seymour *et al.*, 2010). However, a recent UK pilot trial exploring the feasibility of an ACP intervention delivered by an experienced nurse facilitator, found families of people with advanced dementia were reluctant to engage in advance planning (Sampson *et al.*, 2011). People with dementia may assume their relatives are willing to undertake such responsibilities but family carers may feel unprepared for, and avoid, such important decision making around end of life care (Ayalon

*et al.*, 2012). Importantly, it has been found that the wishes and preferences of people with dementia and carers may differ and it cannot be assumed that choices made by carers reflect the views of a person with dementia (Denning *et al.*, 2012).

### Limitations of the study

This study has sought to explore the views of people with mild to moderate dementia about ACP; a recent review identified this as an important evidence gap (Denning *et al.*, 2011). However, a limitation of this research is that data collection was carried out in one geographical area of England; this may influence the generalizability of the findings. We have no reason to believe that other areas of the UK have broader experience of putting ACP into practice but we may have recruited only those families interested in future planning, so the levels of public interest in ACP may be even less in the wider community. In addition, most of the participants had close family living nearby; there is reason to believe that their experiences may be very different to those people living alone with no relatives geographically close (Samsi and Manthorpe, 2011). Samsi and Manthorpe (2011) found that people living alone without close relatives experienced difficulty in appointing a suitable person to hold LPA or to ensure their wishes and preferences were carried out when they had no direct or even distant next of kin.

### Implications for clinical practice

Timing was a key issue: participants found it difficult to know when was the best time to undertake ACP particularly the completion of formal documents, with the exception of LPA for property and affairs. There may be a critical point at which people with dementia cannot engage in ACP (Denning *et al.*, 2011). (Hirschman *et al.*, 2004) suggests this might be at MMSE scores less than 18–20. However, although a MMSE score is useful in determining if a person is capable of undertaking ACP, it should not be a substitute for assessing a person's capacity to understand and make a decision about a specific situation (Department of Constitutional Affairs, 2007). Indeed research has shown that people in the advanced stages of the illness are able to participate in end of life decisions (Godwin and Waters, 2009). Participants in our research suggested that the time of diagnosis was unsuitable for ACP since it was too soon. Nonetheless, Gillick (2010) has suggested that the on-going process of ACP should start early, perhaps using videos to aid understanding, and continue with the help of surrogates throughout the course of the condition. Memory clinic staff also appear

reluctant to engage during the time of diagnosis (Cavalieri *et al.*, 2002) and unfortunately some patients may be too cognitively impaired when they present (Banerjee *et al.*, 2007). There are other opportunities to introduce ACP along the dementia care pathway, for those who wish to make such plans, including medication review appointments and entry into a care home; the latter, however, may be too late (Robinson *et al.*, 2012). Whatever the timing, it is important that health and social care professionals reassure people with dementia and their carers that such plans can, and should, be reviewed regularly (Seymour *et al.*, 2004).

This study revealed that people in the early and moderate stages of dementia felt they received little information and support to help them undertake ACP. People in the early stages of dementia have been shown to receive little formal professional support, especially around information provision (Manthorpe *et al.*, 2011) unless they are receiving dementia drugs or have access to local peer support or dementia advisor schemes. Family carers feel they require information about ACP but not until the later stages of the illness, which may be too late (Robinson *et al.*, 2012). In addition, lack of choice in future care options was a key barrier. Despite increasing research internationally to improve the quality of end of life care in dementia there are still significant numbers of people with advanced dementia who die in hospitals (Houttekier *et al.*, 2010) and very few access hospice care. Alternative models for service provision for end of life care in dementia have been developed, such as dementia-specific hospice care in the US (Shega and Tozer, 2009) and nursing home physicians in the Netherlands (Hertogh, 2010). In England, despite a national and local initiative to improve the quality of end of life care in dementia (National Institute for Clinical Excellence, 2010), people with advanced dementia still appear to be a disadvantaged group in terms of access to care options (Sampson and Robinson, 2009).

### Conclusion

People with mild to moderate dementia and their families exhibit a willingness to plan ahead with respect to personal, practical, and financial planning. However, they are reluctant to engage in future health and care planning preferring instead to trust family carers and known health professionals to engage in “best-interest” decision making; in England and Wales this follows best practice recommendations (Department of Constitutional Affairs, 2007; Nuffield Council on Bioethics, 2009). In terms of nominating a trusted

relative, many of our participants were aware of and had completed LPAs for property and affairs. There are opportunities, however, for a wide range of professionals (health and social care, legal, and voluntary representatives) to build on people's preferences for informal planning by exploring the assumptions underlying them, providing information about the possible illness trajectory and care options available. Health and social care professionals also have a role to play in highlighting the aspects of ACP which seem to be most relevant to the wishes and aspirations of people with dementia.

### Conflict of interest

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### Description of authors' role

Dickinson was involved in the data collection, data analysis, and interpretation and the drafting of the paper. Bamford was involved in the study design, data collection, data analysis, and interpretation and drafting of the paper. Exley was involved in the conception and design of the study, obtaining funding, data analysis, and interpretation and drafting of the paper. Emmett was involved in study design and critical review of the paper. Hughes was involved in study design, participant recruitment, and critical review of the paper. Robinson was principal investigator with responsibility for study management and involved in drafting of the paper.

All authors have seen and approved the final version. All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

### Role of the funding source

The funders had no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the paper; a copy of the paper was sent to the funders prior to submission.

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